

**GLOBAL
HEALTHY
LIVING
FOUNDATION**

april
2021

COVID-19
Patient Impact & Insights

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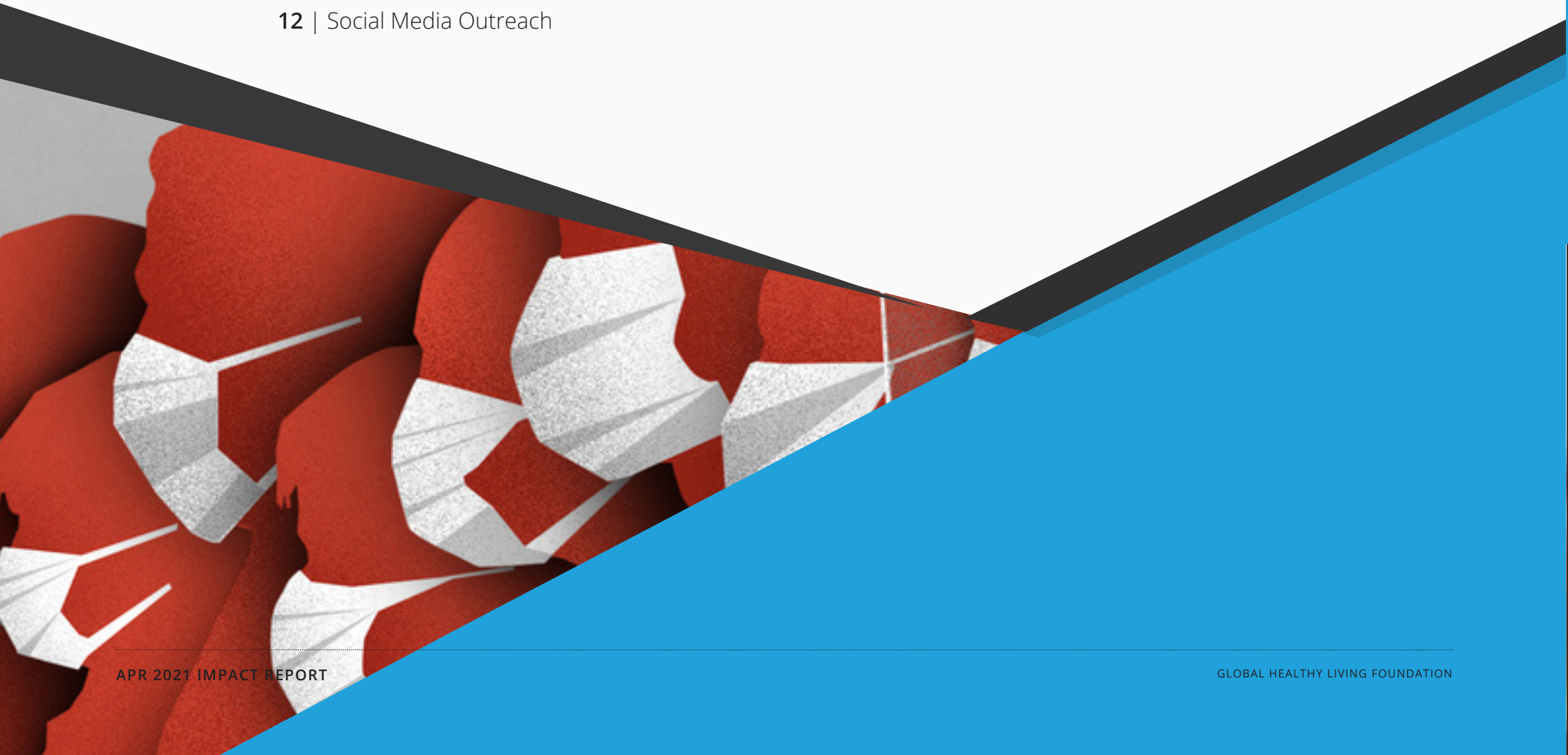
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COVID-19 PATIENT IMPACT & INSIGHTS



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GHLF COVID-19 PATIENT SUPPORT PROGRAM FOR CHRONIC ILLNESS PATIENTS

In mid-March 2020, GHLF launched a patient support program for people living with chronic illness to help them navigate the coronavirus pandemic — **whether they have COVID-19 or not.**

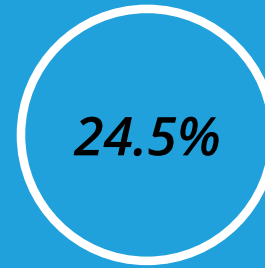
Informed by our COVID-19 Patient Leadership Council, the program is growing rapidly and meeting underserved needs of high-risk and chronic illness patients. [Go to www.GHLF.org](http://www.GHLF.org) to learn more



NUMBER OF MEMBERS



NUMBER OF SUBSCRIBERS



EMAIL OPEN RATE
(HEALTH INDUSTRY AVERAGE = %22*)



EMAIL CLICK RATE
(HEALTH INDUSTRY AVERAGE = %2.5*)

Source: Mailchimp Email Marketing Benchmarks

TOP CONDITIONS



31%

RHEUMATOID ARTHRITIS



19%

LUNG DISEASE



13%

PSORIATIC ARTHRITIS + PSORIASIS



15%

FIBROMYALGIA



13%

HEART DISEASE



11%

MIGRAINE



9%

DIABETES



7%

INFLAMMATORY BOWEL DISEASE

PATIENT SUPPORT PROGRAM COMMUNITY POLLS

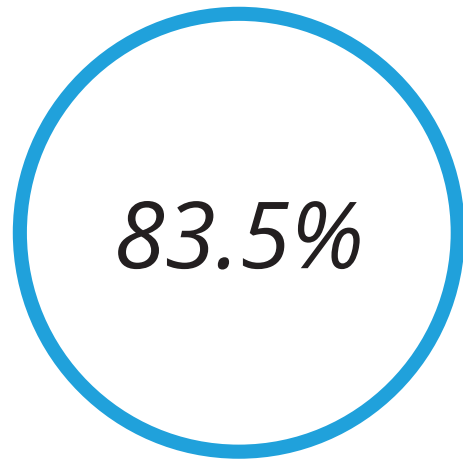


We are surveying our Patient Support Program members regularly about important issues in health care and other topics.

EMOTIONS AROUND THE COVID-19 VACCINE POLL

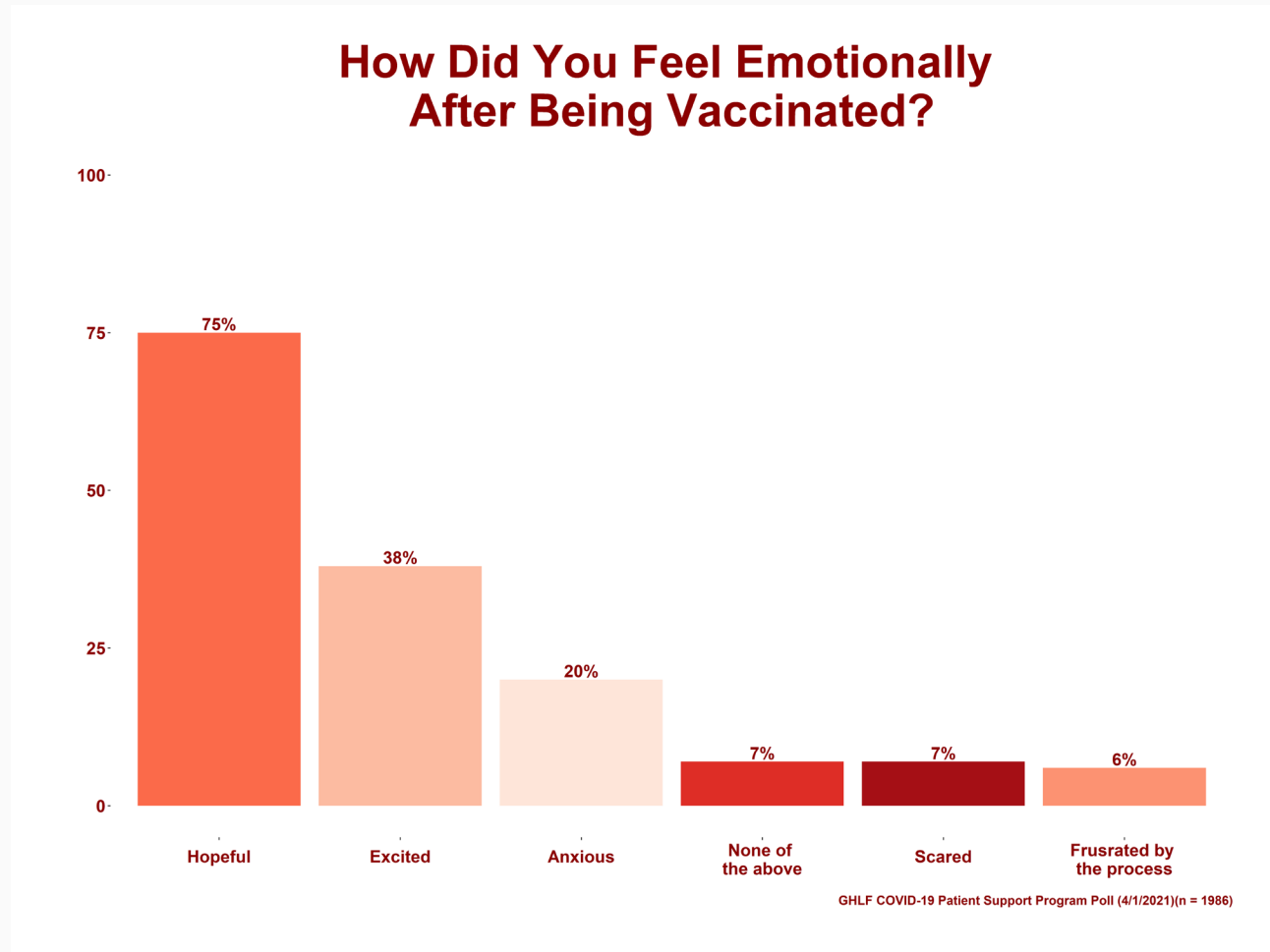
A TOTAL OF 2,379

Patient Support Program subscribers responded to our April quick poll on their emotions before and/or after being vaccinated.

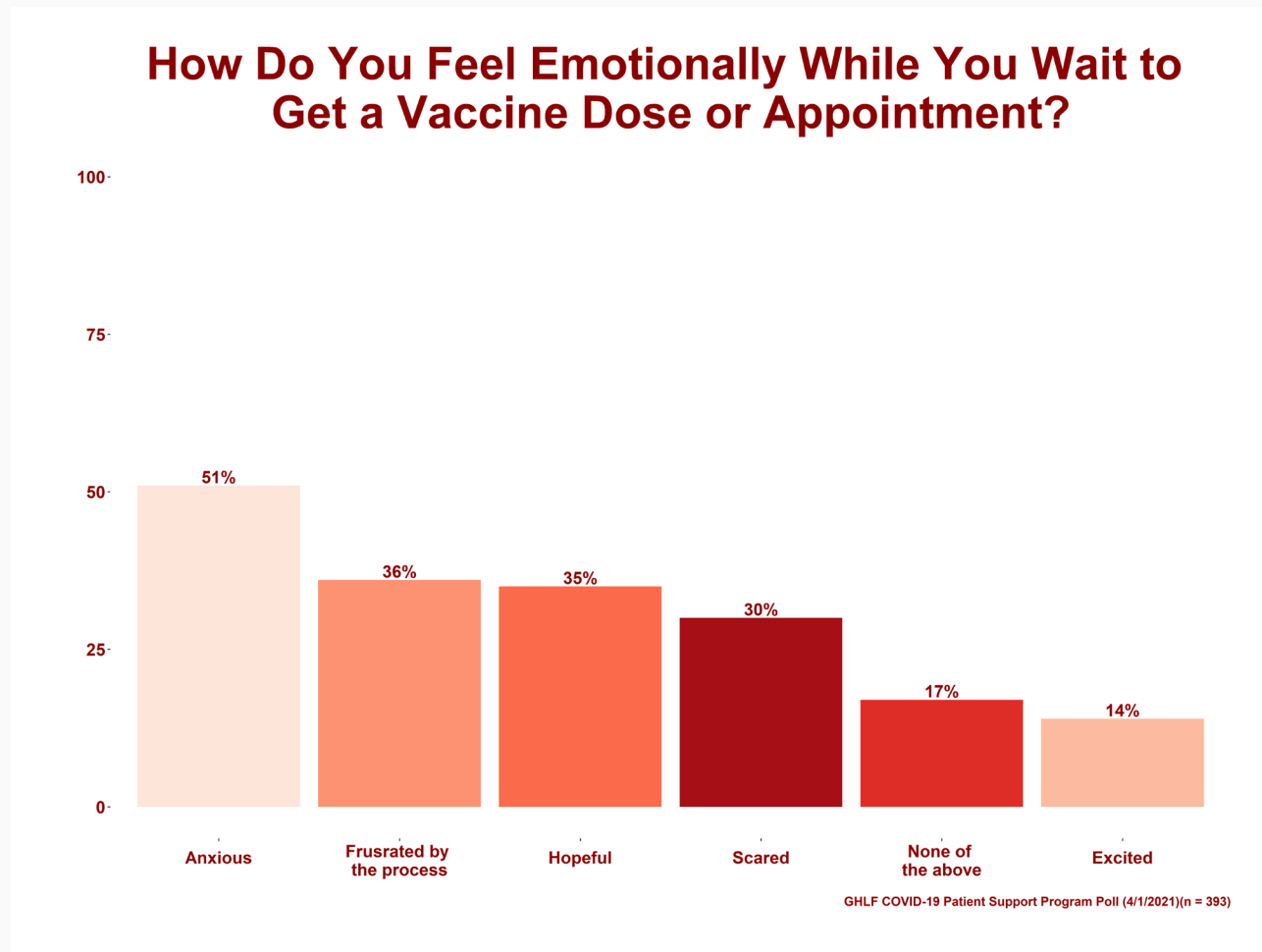


**HAD ALREADY RECEIVED AT LEAST ONE DOSE
OF THE CORONAVIRUS (COVID-19) VACCINE.**

We asked those who already received a dose of the vaccine how they felt emotionally after being vaccinated. Here are the responses:



We also asked those who have yet to be vaccinated how they felt emotionally while waiting to get a dose of the vaccine. Here are the responses:



EMOTIONS AROUND THE COVID-19 VACCINE POLL: WHAT RESPONDENTS ARE SAYING

“ I am hopeful and excited to live my life without the fear of getting really sick from COVID if I am to contract it.

I’m excited to have human contact with my loved ones who have been vaccinated, especially my 97-year-old mom.

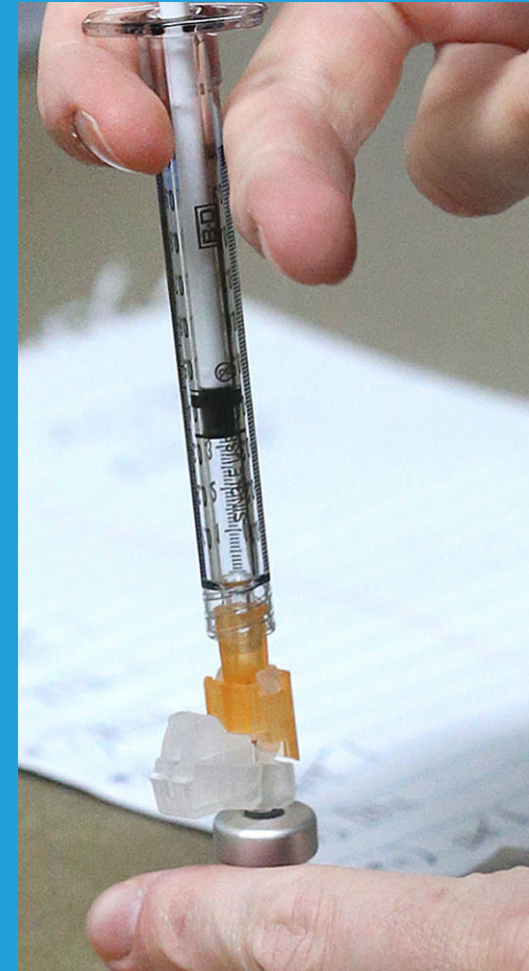
”

“ I’m excited to see my grandchildren again and to be able to hug them.

We’re both so excited for the world to become semi-normal.

”

“ I’m a week into my second shot and feel like the whole world has opened back up to me, after being isolated for a year.

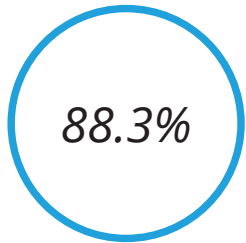


ENTERING A NEW NORMAL POLL

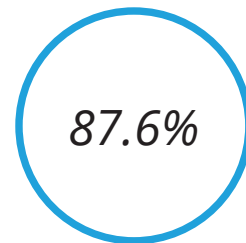
A TOTAL OF 1,421

Patient Support Program subscribers responded to our April quick poll on chronic disease patients' thoughts about entering a new normal as the pandemic fades.

We asked questions about accessibility to events during and after the pandemic.

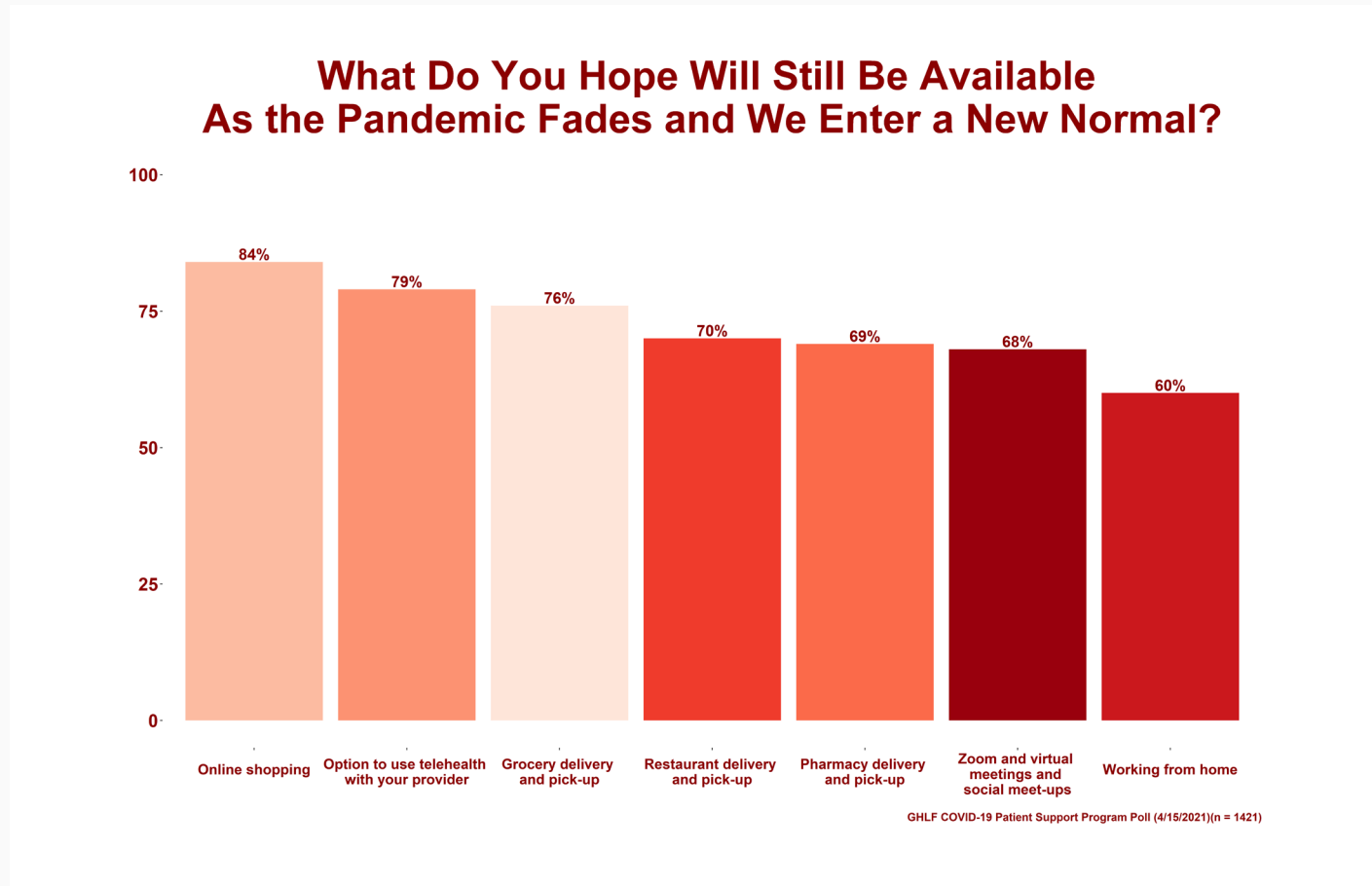


THOUGHT THAT VIRTUAL OPTIONS SUCH AS ZOOM AND TELEHEALTH HAVE MADE IT EASIER TO ATTEND EVENTS, GENERALLY.

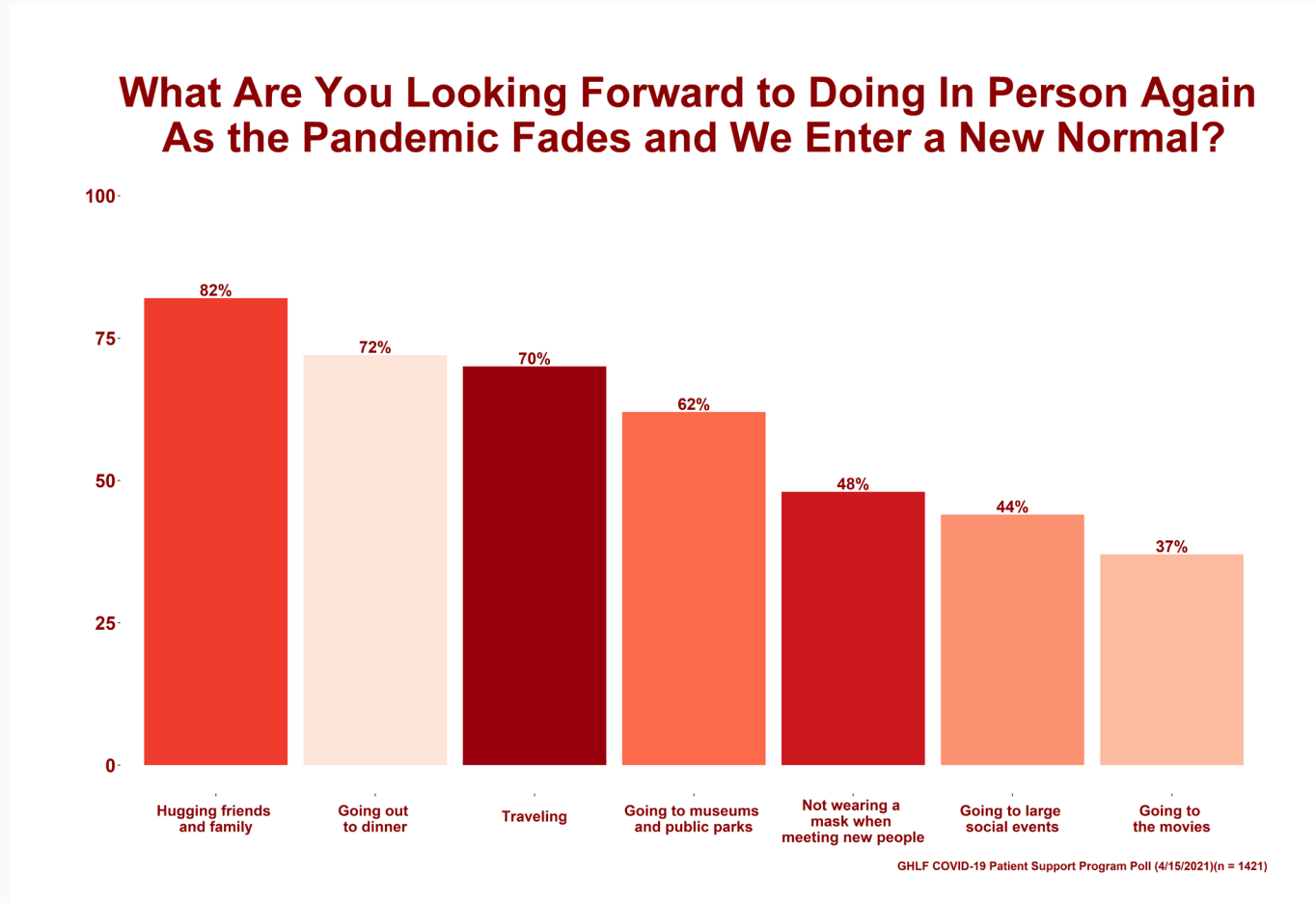


THOUGHT THAT THESE EVENTS AND SERVICES WILL CONTINUE TO HAVE VIRTUAL OPTIONS AS THE PANDEMIC FADES.

We also asked respondents what they hoped would still be available as the pandemic fades. Here are the responses:



In addition, we asked what respondents are looking forward to doing in-person again as the pandemic fades. Here are the responses:



ENTERING A NEW NORMAL POLL: WHAT RESPONDENTS ARE SAYING

We also provided respondents the opportunity to share their thoughts or feelings about what it will be like entering the new normal as a chronic disease patient. Here is a sample of responses.

“ Because of COVID, I have been able to participate in arts and cultural and political events from all over the world. Things I could never have done in my lifetime.

Biggest concern is whether reentry can be the same for us as for others because of the uncertainty about vaccine effectiveness in the immunosuppressed.

“ Hope that society as a whole will remember the perils of those who are immune compromised and continue frequent hand washing and good cleaning practices.



“

My main concern is that people who do not have a chronic disease will go further towards “normal” faster than I feel is safe for me. My disease is “invisible” most of the time and it’s hard when people push me to do more “normal” things then seems safe.

I hope we gain a new sense of responsibility to each other as a result of living through the pandemic.”

”



RESEARCH UPDATE: PCORI STAKEHOLDER CONVENING ENGAGEMENT AWARD



Global Healthy Living Foundation was awarded a 1-year PCORI Stakeholder Convening Engagement Award for our proposed “Vaccine Uptake Research in Autoimmune Disease: Multistakeholder Planning” project.

This project will bring together a diverse group of stakeholders, including patients, physicians, pharmacists, the CDC, the FDA, and other researchers, to build partnerships for future research in this area. The goal of the project is to create a research agenda for implementing future projects that help improve the understanding and effectiveness of initiatives that increase vaccine uptake among adults with autoimmune conditions. This includes uptake for the pneumonia, shingles, flu and COVID-19 vaccines.



SOCIAL MEDIA



 **CreakyJoints.org** @CreakyJoints · 5h

!! #Vaccine Update: We are actively monitoring the @CDCgov / @US_FDA statement and guidance regarding the J&J vaccine. We understand that this can be very stressful. We encourage you to discuss your concerns with your healthcare providers. Please continue following us for updates.

 **CreakyJoints.org** @CreakyJoints · Apr 22

Today our director of education and digital strategy @JosephCoe met with NY leaders to discuss critical healthcare issues facing our community. Thank you Assemblymember @kenzebrowski_ny for helping New York residents gain access to #Covid19 vaccines.



  15  28 

 **CreakyJoints.org** @CreakyJoints · Apr 1

A big part of why Charles says she posted about her role in the COVID-19 vaccine development is because she firmly believes that it's important for other people in the community to see young, Black, female scientists.



This Pfizer Scientist Helped Develop the COVID-...
Learn more about Darryl Melissa Charles, a Pfizer vaccine research scientist who worked on the ...
ghlf.org

 2  34  66 

 **CreakyJoints.org** @CreakyJoints · Apr 1

cc: @pfizer

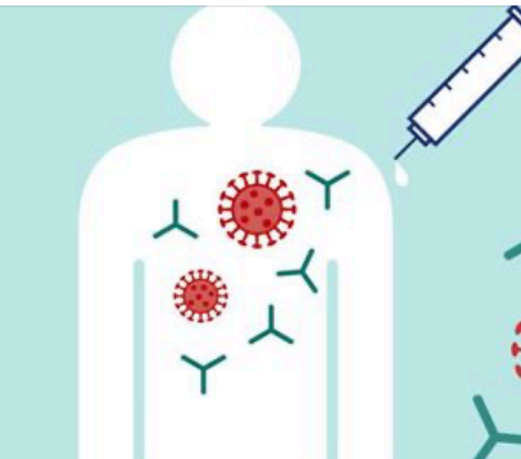
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CreakyJoints
April 3 · 🌐

The U.S. Centers for Disease Control and Prevention (CDC) and the American College of Rheumatology (ACR) do not recommend getting an antibody test after receiving the vaccine to assess immunity.

As always, if you have questions or concerns please contact your healthcare provider(s).



CREAKYJOINTS.ORG
Antibody Testing After the COVID-19 Vaccine: What You're Immunocompromised

CreakyJoints
April 14 at 1:21 PM · 🌐

Take time to grieve

Living with chronic illness means you are no stranger to loss and grief. Grieve and let yourself be sad, and then let the new things begin to emerge for you.



CREAKYJOINTS.ORG
How to Cope with the Return to 'Normal' After COVID-19 Illness

CreakyJoints
April 11 at 2:15 PM · 🌐

During a recent CreakyJoints webinar, Dr. Curtis, Chair of the [American College of Rheumatology](#) (ACR) COVID-19 Vaccine Clinical Guidance Task Force, provided an overview of the ACR's guidance and debunked myths about the COVID-19 vaccine.

Read the recap and listen to the entire discussion:



CREAKYJOINTS.ORG
Webinar: COVID-19 Vaccine: What to Know if You Are Immunocompromised

Last fall, the World Health Organization described COVID-19 as an “infodemic” that inhibited containment efforts by governments and health care organizations alike.



[Going viral: Squaring off against social media’s medical misinformation ‘infodemic’](#)

“

“This is why it is so important for patients to have access to trusted, up-to-date and actionable information that meets every patient’s health literacy standards and is specific to their rheumatologic conditions,” Joseph Coe, MPA, director of education and digital strategy at the Global Healthy Living Foundation said in an interview.

SPANISH-LANGUAGE UPDATE

We continue to provide up-to-date information during the COVID-19 pandemic, focused on addressing doctor-patient relationships, vaccine information, and wellness through our CreakyJoints Español properties:



[Spanish-language COVID-19 Vaccine information](#)



COVID-19 VACCINE EDUCATION



CreakyJoints and the Global Healthy Living Foundation continue to regularly publish new resources to help patients with chronic conditions navigate the COVID-19 pandemic.

We are reaching many thousands of rheumatic and inflammatory disease patients each day with information about COVID-19 vaccines that is targeted to them. New resources published over the past four weeks include:

Over the last month, top content has continued to focus on COVID-19 vaccines. There is a huge dearth of information — and plenty of misinformation — regarding COVID-19 vaccines for people who are immunocompromised, take immunosuppressant medication, and have autoimmune conditions.

[The Johnson & Johnson COVID-19 Vaccine Blood Clot Issue: What Autoimmune and Inflammatory Disease Patients Need to Know](#)

[What the CDC's New Guidance on Travel for Fully Vaccinated People Means If You're Immunocompromised](#)

[Most Inflammatory Disease Patients on Immunosuppressants Mount a Response to the COVID-19 Vaccine \(But Can Vary a Lot by Medication\)](#)

[Antibody Testing After Getting the COVID19- Vaccine: What to Know If You're Immunocompromised](#)

COVID-19 VACCINE EDUCATION: A FOCUS ON INFLAMMATORY RHEUMATIC CONDITIONS



In order to reach people who are specifically searching for information about the COVID-19 vaccine and their health condition, we created the following resources.

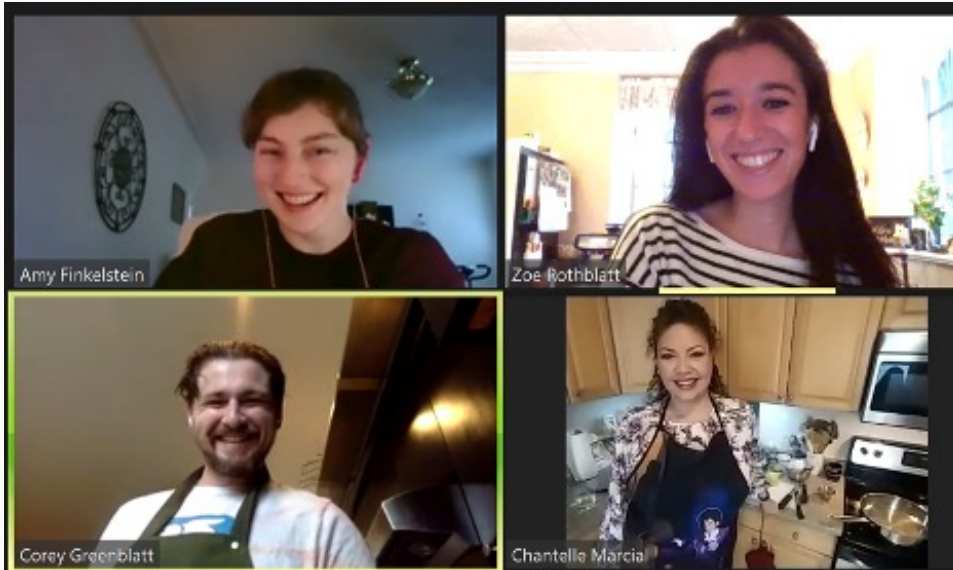
We hope these resources provide reassuring information about safety and efficacy in order to increase vaccine confidence.

[Axial Spondyloarthritis and the COVID-19 Vaccine: What You Need to Know](#)

[Psoriatic Arthritis and the COVID-19 Vaccine: What You Need to Know](#)

[Rheumatoid Arthritis and the COVID-19 Vaccine: What You Need to Know](#)

CREAKYKITCHEN



CreakyKitchen Episode 6: CreakyKitchen's Celebration of Spring Vegetables

We continue to provide much needed entertainment during the COVID-19 pandemic. CreakyKitchen events provide a way for our community to join together in a fun and stress-free environment to share strength and experience when it comes to cooking and nutrition.

In Episode 6, CreakyKitchen planned for sunny days ahead. Guest Chef, Chantelle Marcial shared her recipe for a veggie packed Pasta Primavera. Charis Hill walked us through their garden and shared their tips for maintaining a garden when you have arthritis. Co-hosts Zoe Rothblatt and Corey Greenblatt answered the most common questions the CreakyJoints community had about gardening.

ADVOCACY AND POLICY UPDATE

GHLF continues to submit letters to policymakers around the country to ensure patients have access to care without obstacles, especially now during COVID-19. We have been focused on protecting patient access to medication and raising the voice of patients living with chronic disease.

Take a look at the comment letters:

- [Letter to CMS About Step Therapy and Part B](#)
- [Letter in Support of Florida House Bill 1373](#)
- [Letter to Congress in Support of House Resolution 135](#)

We continue to focus on stopping the growth of copay accumulator adjuster programs. The op-ed entitled [“When health care costs more than your house, you have to make hard choices”](#) by Elisa Comer, 50-State Network patient advocate, was published in the Tennessean.

“

“I choose to believe that American health care exists for the patients it’s supposed to serve. So I advocate and tell my story in support of [House Bill 0619 and Senate Bill 1397](#), which will protect thousands of Tennessee patients by ensuring they can use valuable patient assist programs, regardless of whether they are in their deductible corridor with their insurance.” – Elisa Comer



PATIENT LEADERS IN OUR PATIENT SUPPORT GROUP

From left:

Top row: Jovana Gonzalez Placido (Scleroderma), Daniel Garza (HIV/AIDS), Susan Herley (Gout), Tinu Abayomi-Paul (Cancer), Molly Schreiber (Diabetes), Terrance Hill (Sickle Cell Disease), Peter Morley (Lupus)

Middle row: Jed Finley (Ankylosing Spondylitis), Jamie Holland (Crohn's Disease), Charis Hill (Ankylosing Spondylitis), Beth Madison (Lupus), Jennifer Walker (Asthma)

Bottom row: Ebby Isbill (Multiple Sclerosis), Catherine Charrett-Dykes (Migraine), Dawn Gibson (Ankylosing Spondylitis), Roxanne Watson (Heart Disease), Diane Talbert (Psoriasis & Psoriatic Arthritis), Ray Bouchard (Rheumatoid Arthritis), Eileen Davidson (Rheumatoid Arthritis)

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